Children with Special Health Care Needs (CSHCN): Care Coordination Initiatives

Objective 5.3: Increase the proportion of families of children with special health care needs who receive care coordination supports through cross-system collaboration by 25% by 2025.

Activities During Federal Fiscal Year 2023

HCC Pilot: During FY23, the HCC Consultant worked with two pilot sites (Coffey Health System and Redbud Pediatrics) to train and employ a care coordinator for their COVID-19 response. Title V staff supported the two sites through onboarding, monthly check-ins, and an ECHO learning series. The care coordinators were trained on the National Care Coordination Standards for Children and Youth with Special Health Care Needs and asked to focus on any of the following areas: screening; assessing need; developing shared plans of care; building communication with care team, patients, and community partners; child and family empowerment and skills development; care transitions. Care coordinators working directly on COVID-19 relief were asked to screen for needs, assess levels of need, and connect families to needed resources. The HCC consultant also provided support on data requirements so the program can be effectively evaluated upon completion.

Bridges Care Coordination Moving from Pilot to Program Services: The Bridges program was designed to support children and families as they are transitioning out of the Kansas Early Childhood Developmental Services (KECDS, formally called Infant Toddler Services) upon the child's third birthday and into the Early Childhood Special Education (ECSE) services or community services. This is a time that many families have expressed a feeling of being overwhelmed in knowing how to navigate the systems of care for their child. Bridges was designed to help fill that challenge by providing holistic care coordination services to provide a smooth and stress-free experience for the child and their family.

The Bridges program expanded over the last year to add two additional pilot communities (Miami and Crawford counties), which added greater capacity to refine the program and solidify the transition from a pilot to a service offering of the KS-SHCN program. The Bridges program is one more step to move towards providing services and supports to the larger CSHCN population in Kansas. Additionally, outreach on the Bridges program was conducted by a parent representative/care coordinator for the program to try and recruit additional participants into the program.

Monthly touch point meetings were held with each BCC to provide ongoing support and assistance. Trainings were offered as one-on-one trainings and coaching between the BCC's and the CYSHCN Director during the monthly touch points. Quality improvement and quality assurance measures are used to monitor fidelity and program outcomes.

Family Systems Navigation Trainings: KS-SHCN offered four trainings across the state for families of CSHCN. KS-SHCN worked with community partners, grantees, and SO staff to plan and implement these trainings at different locations across that state in both English and Spanish. Each of the trainings had great attendance and the information was well-received. Based on feedback from these trainings and the Family Advisory Council, KS-SHCN is looking at refining the curriculum to better align with the needs of Kansas families.

Local MCH Agencies:
The following are examples of how some of the local MCH grantee agencies have made progress toward objective 5.3 during the reporting period.

- Barton County Health Department, which has experienced staff vacancies throughout the year, met their goal to have new staff trained on utilizing the IRIS system which will aid in coordination of services for CSHCN.
- Crawford County Health Department's CSHCN satellite office followed the holistic care coordination model in providing services to clients and their family. The SHCN care coordinator completed Education Advocacy training and attended IEP meetings as a support person as needed to ensure smooth education transitions. They had a family that was very grateful for care coordination services that helped them obtain a special car seat through Safe Kids Kansas. They were so impressed to have a certified installer deliver and install it in the vehicle for them.
- Miami County Health Department SHCN program staff had been working since SFY22 to get a client approved for services. Her diagnosis, epidermolysis bullosa, is not on the decision schema, so her only way to be eligible for services was through SSI. The client wears expensive gloves due to her diagnosis and insurance does not cover them. Through a special bequest meeting MCHD was able to get her gloves ordered through the program. Mom received the gloves and was so appreciative for the financial relief it brought her family. They also assisted a family with obtaining and AngelSense tracker for their child with autism, to provide peace of mind when it came to the child's safety.
- Nemaha County Community Health Services (NCCHS) care coordinator is served a family that expressed appreciation for the timeliness and content of information provided to them. The family received necessary medical supplies covered by CSHCN that insurance would not cover. Prior to connecting with the CSCHN program and the medical supplies they were provided, the family was traveling an hour and half (one-way) to the ER to receive a replacement of the medical supply when the one they were using was leaking or faulty. Before CSHCN stepped in, it was the only way to get their supply costs covered.
- Neosho County Health Department (NCHD) had a set of parents come to them and share challenges with communicating with their child who has autism as well as the child's lack of sleep. NCHD worked with the parents, the child's physician, and the special bequest team to get the child tablets and a safer bed for sleeping. The parents reported better communication and rest for the whole family.

- Riley County Health Department (RCHD) maintained a strong community network to ensure their CSHCN clients are linked to care. They refer CSHCN to the nearest CSHCN Satellite Office at Nemaha County Community Health Services Inc. (NCCHS). They also stayed connected to the Infant Toddler Services (ITS) Network in Riley County and referred clients to free community screening events hosted by USD 383. They supported MCH clients and their families as they transitioned from an IFSP to an IEP. There can be many moving pieces for families who are experiencing these transitions and RCHD staff has the knowledge to provide adequate support during that time. In addition to ITS, NCCHS, and USD 383, RCHD MCH staff coordinated services with the following agencies that have mutual clients with SHCN: Department of Family and Children, Family Preservation, Three Rivers (empowering person with disabilities and Seniors to live, work, and be active members in their communities), Pediatrics, and Kancare.

Plans for Federal Fiscal Year 2025

Holistic Care Coordination: SHCN Program: Kansas Title V continues to use the National Care Coordination Standards for Children and Youth with Special Health Care Needs developed by the National Academy for State Health Policy as the guiding framework for the holistic care coordination services provided to clients on the KS-SHCN program. KS-SHCN program continues to grow a network of referral sources for issues including, but not limited to, medical complications, behavioral health conditions, assistive technologies, surgery providers, physical therapists, and education assistance. Care Coordinators will continue to attend trainings and webinars to maintain knowledge of community partners and referral sources to best provide services for families within SHCN.

The HCC work continues to be foundational within the Title V work. While originally developed for use by the KS-SHCN program, the long-term vision is to spread and scale to other providers across the state and within other Bureau of Family Health programs. The KS-SHCN program continues to use the HCC approach with all clients on the program who meet medical or SSI qualification standards.

Systems Navigation Training for Families: Systems Navigation Training for Families (SNTF) materials will be reviewed during FY25 by the CYSHCN Director, the SHCN Program manager, and the Screening and Surveillance Director. During this review, new trainers, who have experience with children and youth with special health care needs, will be selected and trained. By the end of FY25, there will be at least two planned trainings for families in the state. Title V continues to see the value of these trainings for families who have children with special needs and want to learn more about services and supports in Kansas and how to effectively navigate them. These trainings not only provide education and resources to families but also provide an opportunity for peer-to-peer support between participants.

Systems Navigation Training for Youth: Systems Navigation training for Youth (SNTY) will be developed in coloration based on the SNTF curriculum through the collaborative

efforts of the CYSHCN Director and the Child & Adolescent Consultants. More information on SNTY can be found in the Child Plan Narrative.